State of Utah

Comprehensive Plan For Public Services in the Most Appropriate Integrated Setting

March 26, 2002

INTRODUCTION

This document is Utah's plan for providing services in the most integrated setting for people with disabilities. Although Utah's efforts began before the United States Supreme Court's opinion in *Olmstead v. L.C.*, the direction taken by the State is consistent with that decision both in letter and in spirit. Like any working plan responding to a particular group, this comprehensive plan must be viewed in the context of the state's responsibility to all groups and all of its citizens. The United States Supreme Court in *Olmstead* recognized that a state plan must be balanced and may consider resources available to the state. State policy makers, both in the executive and legislative branches, must be cognizant of the state's finite resources and the demand for services that are growing and dynamic. This plan reflects the commitment and good faith of policy makers and professionals who are committed to providing services for people with disabilities. It also represents a rational balance between necessary fiscal responsibility and sincere hope for better services and programs for an important part of our population.

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STATE OF UTAH
COMPREHENSIVE STATE PLAN FOR PUBLIC SERVICES IN THE MOST APPROPRIATE INTEGRATED SETTING

(Includes State Response to the Olmstead Decision)

March 26, 2002

I. PREFACE

The State of Utah has long recognized the importance of providing services to qualified individuals with disabilities in the most integrated setting possible. Over the last twenty years, the State has worked diligently to expand access to a broad array of long-term care services for persons of all ages who experience chronic functional impairments. As developing technological advances allow individuals to receive appropriate care in settings other than hospitals, nursing homes, specialized institutions and non-institutional long-term care, provider systems have entered the health care delivery network, and Utah has proactively utilized public policy and publicly-funded health care programs to enhance the quality and scope of services. Long before the U.S. Supreme Court decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), Utah has been focused on providing services not only in the least restrictive environment possible, but also based on client involvement and informed choice. (For example, as recently as 1997, the State's Health Policy Commission focused attention on the direction of long-term services by establishing the Long Term Care Technical Advisory Group (LTC TAG). The LTC TAG conducted a Comprehensive Long Term Care Public Policy Study to develop unifying public policy, known as *Health Print*.) In addition, advocates, consumers and public agencies have been meeting on identifying needs and barriers as it relates to the *Olmstead* decision since 1999. This group has been instrumental in establishing *Olmstead* Advisory Subcommittee groups to work on numerous issues and projects, and has helped develop this document.

Although this Comprehensive State Plan for Public Services in the Most Appropriate Integrated Setting ("Plan") refers to the *Olmstead* decision, this Plan is broader than *Olmstead*, and it is meant to reflect the overall direction and planning process for public services provided to the diverse disabled population served by the long-term care system. (For the purposes of this Plan, the term "disabled population" refers to individuals who are disabled as a result of a physical condition (including the elderly), mental illness, mental retardation or a developmental disability.) This Plan is also intended to be a dynamic and evolving document.

Demographics Profile

A demographic context is important to understand the scope and scale of current services provided and of planned needs and actions. The 2000 Census places Utah's total population at 2,233,169. This represents an increase of 29% from the 1990 population and makes Utah the 4th fastest growing state in the country between 1990 and 2000. Utah comprises 29 counties encompassing 84,900 square miles. Seventy-six percent (76%) of the state's population reside in the counties of Salt Lake, Davis, Weber and Utah.

Individuals over the age of 65 represent 8.5% of the Utah population with those over the age of 75 comprising 4% and those over 85 comprising 1%. The average life expectancy in Utah is the fourth highest in the nation with an expectancy of 86 for women and 82 for men in Utah as compared to 81 for women and 74 for men in the United States as a whole. While Utah remains one of the youngest states in the U.S., the elderly population is also growing at a dramatic rate.

Incidence data for mental illness estimates the occurrence of serious mental illness among the adult population to be 2.6% and among children and youth age 10 to 18 to be 8%. Based on this estimate, there are 39,366 adults with serious mental illness in Utah and 57,526 children.

In addition, Utah ranks second highest in the nation for total number of dependents (youth and aged) versus working individuals. According to the 2000 Census, Utah's dependency ratio is 68.6 non-working for every 100 working. The U.S. average is 61.7.

Based on a developmental disability incidence rate of 1.7%, there is estimated to be 37,964 individuals with developmental disabilities in Utah. Based on a mental retardation incidence rate of 0.51%, there is estimated to be 11,389 individuals with mental retardation in Utah. As of 2020, with projected Utah population of 2,781,000 it is projected 47,280 will have a developmental disability and 14,180 will have mental retardation.

Based on the increasing demographics, there is a strong potential for increased demand on the long-term care system. While individuals are living longer and healthier, there will be individuals with functional disabilities needing assistance in order to remain in their own homes or in some type of community living.

Affected Agencies

The *Olmstead* planning process for the State of Utah is a joint effort of the Governor's Office of Planning and Budget (GOPB), the Department of Health and the Department of Human Services (as well as consultation with the Office of the Attorney General). Many agencies are involved in the State's long-term care system, and are therefore affected by this Plan. They include the following State Departments, Divisions and Agencies:

- **Department of Human Services (DHS)**
  - Division of Aging and Adult Services (DAAS)
  - Division of Child and Family Services (DCFS)
  - Division of Mental Health (DMH)
  - Division of Services for People with Disabilities (DSPD)
  - Division of Youth Corrections (DYC)
- **Department of Health (DOH)**
  - Division of Health Care Financing
  - Division of Health Systems Improvement
  - Bureau of Program Certification and Residential Assessment
- **Department of Community and Economic Development (DCED)**
- **State Board of Education**
  - Office of Rehabilitation Services (Voc Rehab)

- **Department of Workforce Services (DWS)**

Acknowledgements

We wish to acknowledge the following interested parties who participated or provided input toward the development of this Plan:

- ARC of Utah
- Community Action Program
- Disability Law Center (DLC)
- Disabled Rights Action Committee (DRAC)
- Federal Partners
  - Administration on Aging
  - Health Care Financing Administration
  - Office of Civil Rights
- Governor's Council for People with Disabilities
- Legislative Coalition for People with Disabilities
- Local Area Agencies on Aging Network (AAA's)
- Local Mental Health Authorities
- Mental Health Planning Advisory Council
- National Alliance for the Mentally Ill (NAMI)
- Neighborhood House
- Schools for the Deaf and Blind
- United Cerebral Palsy Association
- Utah Association of Community Services
- Utah Health Care Association
- Utah Independent Living Center
- Utah Independent Living Council

II. LEGAL BACKGROUND

The law creating and protecting the rights of people with disabilities has evolved as our collective understanding of disabilities has improved. We, as a nation, have moved from protecting the public from people with disabilities, to protecting the safety of people with disabilities in institutions, and on to protecting the rights of the disabled to live in the most integrated setting appropriate to their needs. The evolution of disability law has recently culminated in the United States Supreme Court decision of *Olmstead v. L.C*, 527 U.S. 581 (1999). It is with the development of the law and the *Olmstead* decision in mind that this plan is created, in an effort to fully provide for the needs of disabled individuals, in an equitable manner, while mindful of the fiscal responsibilities and limitations of Utah State government.

The Law Prior to Olmstead

Prior to the 1970's, laws protected the safety of institutionalized individuals rather than any substantive rights to particular services. In the 1970's, legislation and court decisions began to recognize that individuals with disabilities have constitutionally protected liberty interests beyond fair admission practices and safety while in institutions. Congress enacted legislation promoting the rights of individuals with disabilities outside of institutions, including Section 504 of the Rehabilitation Act of 1973, and the Education for all Handicapped Children Act of 1974. In 1982, the United States Supreme Court ruled in *Youngberg v. Romeo*, 457 U.S. 307 (1982), that individuals in institutions have a right to physical safety *and* appropriate services. On July 26, 1990, the President signed into law the Americans with Disabilities Act ("ADA"). The ADA prohibits state and local governments from discriminating against people with disabilities in providing public services, and requires that services, programs, and activities are administered in the "most integrated setting appropriate to the needs of qualified individuals with disabilities." The development of the law through legislation and court decisions has empowered people with disabilities to assert rights and address grievances through the legal process. The *Olmstead* case presented the Court with the assertion of individual rights under the ADA.

The Olmstead Decision

The United States Supreme Court decision in *Olmstead v. L.C.,* 527 U.S. 581 (1999), provides an interpretation of the requirements of Title II of the ADA. The *Olmstead* case arose in Atlanta, Georgia and involved two women (identified by the initials L.C. and E.W.) who were diagnosed with mental retardation and mental illness. These women were receiving services in a state psychiatric hospital, but had each requested placement in the community. Despite their doctors' conclusion that placement in a small, community-based group home would more appropriately suit their needs, L.C. and E.W. remained in the state hospital for several years, because there were no community placements available. The two women, along with others, were on a waiting list for community-based services.

The *Olmstead* Court provided an extensive review of the existing law. Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." To further clarify the meaning of Title II of the ADA, the United States Attorney General issued two regulations, which the *Olmstead* Court also discussed. The first, called the "integration regulation," requires a public entity to administer programs in the most integrated setting appropriate to the needs of qualified individuals with disabilities. The "most integrated setting" means a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible. The Court emphasized, however, "that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings." *Olmstead*, 527 U.S. at 601-02.

The second regulation, called the "reasonable modifications regulation" requires public entities to make reasonable modifications to avoid discrimination on the basis of

disability, but does not require measures that would fundamentally alter the nature of the entities' services and programs. The *Olmstead* Court stated that in examining a fundamental alterations claim, a reviewing court must consider, in view of the resources available to the State, not only the cost of providing community-based care to the individuals before the court, but also the range of services the State provides to others with disabilities, and the State's obligation to mete out those services equitably.

By way of example, the *Olmstead* Court went on to explain that "if the State were to demonstrate that it had a comprehensive, effectively-working plan for placing qualified persons with disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State's endeavors to keep its institutions fully populated, the reasonable modifications standard would be met." *Olmstead*, 527 U.S. at 605-06.

Ultimately, the *Olmstead* Court held that under Title II of the ADA, states are required to provide persons with mental disabilities with community-based treatment rather than placement in institutions, where: (1) the State's treatment professionals have determined that community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the community placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities. The Court clarified its holding, stating that it did not hold that the ADA requires States to provide a certain level of benefits to individuals with disabilities. Rather, States must adhere to the ADA's non-discrimination requirement with regard to the services they in fact provide. The Court also cautioned that "the State's responsibility once it provides community-based treatment to qualified persons with disabilities is not boundless." *Olmstead* 527 U.S. at 603.

By creating this Plan, Utah is implementing the requirements of the ADA as set out in the *Olmstead* decision.

Utah's Basic Guiding Principles

In April, 1999, two months before the Supreme Court issued its decision in the *Olmstead* case, Utah's Lt. Governor, Olene Walker, issued a set of guiding principles entitled "Principles to Guide the Delivery of Publicly Funded Services for People with Disabilities in Utah." *(See Attachment 1)* These principles were developed by a group of individuals representing the Governor's Office, the State Legislature, state agencies, providers, and parent advocates. The principles were distributed in the community and opened up for discussion and comment at a public meeting conducted by the Lt. Governor on April 13, 1999. The Department of Human Services and the Department of Health subsequently adopted these principles to guide them in their provision of services.

III. HISTORY OF INSTITUTIONAL SERVICES IN UTAH

Utah currently has an array of services available to serve people with disabilities across the long-term care system. These services range from home and community-based services to institutionalized care. This section provides a history of institutional based services and establishes the framework for the State's planning in the long-term care system while incorporating the guidelines from the *Olmstead* decision.

In order to lay the groundwork for Utah's long-term care continuum of services, a picture of the State's institutional resources and a historical perspective is necessary. The following is a list of public or publicly funded, institutional based services available as of June 30, 2001:

- 1 State Mental Hospital (USH) with 384 beds;
- 81 Nursing Facilities with 7,028 Medicaid Certified beds; [1]
- 17 "Swing Bed" hospital facilities with 353 Medicaid Certified beds;
- 1 State-administered intermediate care facility for people with mental retardation (ICFs/MR) with 290 beds; and[2]
- 13 private sector administered ICFs/MR facilities with 575 Medicaid Certified beds.

A. Utah State Developmental Center (USDC)

Historical Perspective

Since state governments first acknowledged a public interest in and accepted some fiscal responsibility for disabled citizens, states have made sweeping changes in the philosophy and practice of providing public services. These paradigm shifts have resulted from a growing knowledge about disabilities (i.e., causes, prevention, interventions, and accommodations) and an improving regard for persons who experience disabilities (as evidenced by public laws that affirm and promote their rights, an expansion of publicly-funded services, and greater inclusion by their communities).

State Institution Established

The USDC was established in 1929, and was known as the Utah State Training School during an era when relatively little was known about the causes of mental retardation. Given the limits of knowledge at that time, state policies sought both to shelter and protect people with mental retardation from the larger public, and to protect the public from potentially contracting disabilities through association with disabled individuals. Like other states, Utah built a public institution in a remote location and within a broad perimeter of land that provided a physical barrier between the institution and the nearest rural homes and communities.

[1] This number does not include all privately owned nursing facilities, only those that have beds certified by Medicaid.
[2] Utah State Developmental Center (USDC)

The residential buildings of the original institution reflected the state of the art at the time with large, open dormitories and day rooms in which people could be sheltered and supervised in large groups, with staff ratios as high as one staff member to 60 residents. The first people to live at the institution were persons transferred from the Utah State Hospital in Provo, which had previously been the single state institution for persons with mental illness and mental retardation. Other residents, both children and adults, came from communities throughout the State after their families made the painful decision, usually at the advice of their physicians, to "place" them for their "care and protection." By 1932, the institution served around 160 persons.

Period of Growth

Since its establishment in 1929, the USDC has evolved and improved with each major change in thinking regarding what and how public services should be provided for persons with mental retardation. During the 1930's, both the campus and the services were expanded to include nine residential buildings, a school building, a farm, and various other support services (i.e., carpentry, shoe repair, laundry) in which some individuals received on-the-job training.

The number of persons who lived at USDC reached a peak in 1950 at 1,259. Two large residential buildings were constructed during the 1950's. With the help of federal Hospital Improvement Program (HIP) grant funds, five new and smaller residential buildings were added to the campus in the 1960's. Those federal grants also required and funded richer staff ratios (1 staff member per 6 residents) for the new buildings that housed children and adolescents. In contrast, the older buildings that primarily housed adults remained at staff ratios of 1 staff member to 24 residents or 1 staff member to 32 residents.

Impact of New Federal Laws and Funds

With changes to the Social Security Act in the 1970's, federal Medicaid funding was made available to participating states for any public or private institution that met the requirements of an Intermediate Care Facility for Persons with Mental Retardation (ICFs/MR). With the infusion of Medicaid funds, based on a formula to match state dollars, and with the requirements for ICFs/MR certification, the USDC was able to achieve a significant expansion in its services and staffing levels and an improvement in its physical facilities. The USDC initiated a major remodeling of the newer residential buildings to meet ICFs/MR standards for safety and privacy. Beginning in the late 1970's and continuing into the 1980's, eight new residential buildings were constructed to replace six of the older open dormitory-style buildings that would not meet the newer and stricter health and safety codes. Medical services and supports were enhanced with additions to primary care and nursing services and to the variety of specialists who provided on-campus clinics. Through contractual agreement with the University of Utah, the USDC became a site of rotations for medical students and a center for research.

With the passage of Public Law 94-142 in 1975, all children and youth of school age that lived at the USDC (similar to those who lived in the community) were assured the right to a free and appropriate public education. Responsibility for and funding of special education was assumed by Alpine School District by agreement with the Utah State Office of Education. Consistent with Medicaid requirements, adults at the USDC also had access to individualized day programs of an educational and pre-vocational nature.

Out-Movement from the USDC

The Medicaid funding appropriated in the 1970's for ICFs/MR's allowed not only for service expansion at the USDC, but also for the establishment of a number of privately-operated ICFs/MR's in communities throughout the State. Some of these new facilities were owned and/or operated by persons who had been employed by the USDC where they had gained experience in working with people with disabilities. Around 200 individuals moved from the USDC into these new facilities during the 1970s and the early 1980's.

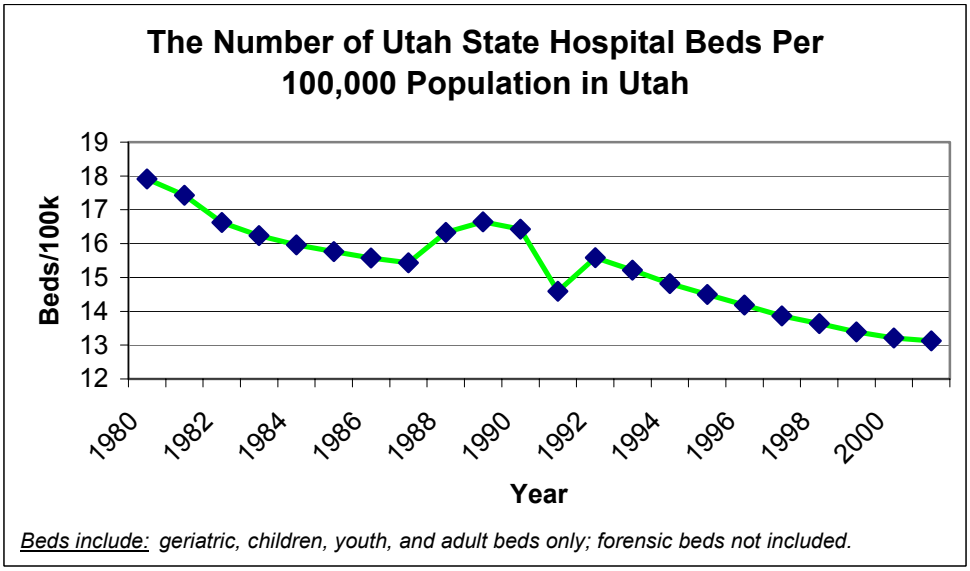
The addition of Home and Community-Based Services waivers also gave a new option for youth and adults who had been living at the USDC to return to their home communities and continue to receive needed services and supports. Over 200 people moved from the USDC and into waiver services from 1986-1990. Most recently, a transfer of individuals from the USDC to their home communities was completed as a result of the settlement agreement reached in the 1989 class action lawsuit of *Lisa P. v Angus.* From 1995 through 2000, 94 persons moved to community-based services based on the recommendations of their treatment teams and parameters of the *Lisa P.* Settlement Agreement. The evaluations completed under the terms of the *Lisa P*. agreement also resulted in recommendations for continued services at the USDC for 166 individuals. In sum, the decline in and stabilization of the USDC census since 1980 is one artifact of expanded options and expectations for community-based services.

B. Utah State Hospital (USH)

Historical Perspective

USH opened its doors in July 1885. The Hospital grew to a maximum census of 1,500 patients in the 1950's and '60's. However, beginning in the mid-60's, community mental health centers, nursing homes, the Utah State Training School (now called the Developmental Center), new medications and other community-based treatments were developed which allowed patients to be discharged from the hospital. In the 60's and 70's USH's population was reduced to 343 beds, where it remained until the last couple of years when additional forensic beds were brought on line.

The State of Utah has made considerable progress at serving individuals in community settings rather than at the USH. Utah has one of the lowest numbers of state hospital beds per capita in the nation. It is important to note that there are significant differences between populations of individuals with mental illness in institutions and aging individuals or individuals with physical or developmental disabilities. Many mental illnesses are episodic with considerable recovery between episodes. Acute hospitalization is thus an appropriate level of care at severe stages of illness and should not be confused with improper restrictive care.



Beds include: geriatric, children, youth, and adult beds only; forensic beds not included.

IV. CURRENT RESOURCES AVAILABLE

Across the long-term care system, various resources are currently available to Utah's diverse disabled population. These resources range from home and community-based services to institutionalization. This document identifies many of these services, which are available across the long-term care system.

The services listed in this section are not all of the available services within the State of Utah. For a complete listing of these and other services, please contact individual agencies. A link to most state agencies can be accessed via the State of Utah's web site: www.utah.gov.

A. Institutional Based Services

Nursing Facilities

Individuals must meet specific admission and eligibility requirements to ensure proper placement within the range of institutional based services and to obtain appropriate levels of services within that placement. Nursing facilities use the following admissions and eligibility criteria:

1. In making the determination that an applicant has mental or physical conditions that can be properly cared for only in a nursing facility, the Department of Health shall document that at least two of the following factors exist:
   a) Due to diagnosed medical conditions, the applicant requires at least substantial physical assistance with the activities of daily living above the level of verbal prompting, supervising, or setting up;
   b) The attending physician has determined that the applicant's level of dysfunction in orientation to person, place, or time requires nursing facility care (or equivalent care provided through an alternative Medicaid health care delivery program); or

c) The medical condition and intensity of services indicate that the care needs of the applicant can not be safely met in a less structured setting, or without the services and supports of an alternative Medicaid health care delivery program.

Nursing facilities can serve any age group, although it is estimated that 85% to 90% of the nursing facility population in Utah consists of elderly adults, with the remaining residents being young disabled adults. Pursuant to federal and state regulation, facilities provide 24-hour medical services including nursing care, dietary services, assisted daily living and comprehensive care planning on a statewide basis.

Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR)

DOH may not authorize Medicaid coverage for an applicant in an ICF/MR, unless the applicant meets the following criteria:

1. The applicant is mentally retarded (except that even if the applicant is mentally retarded, the applicant will not qualify for care in an ICFs/MR if the applicant is ambulatory, continent, only moderately or mildly mentally retarded without complicating conditions, is in need of less than weekly intervention by or under the supervision of a health care professional or trained habilitative personnel, and is capable of daily attendance in a work setting or in day treatment). Day treatment is training and habilitation services outside the nursing facility that are:
   a) intended to aid the self-help and self-sufficiency skill development of a mentally retarded resident;
   b) sufficient to meet the specialized rehabilitative service requirements of 42 CFR 435.1009 for the mentally retarded; and
   c) coordinated with the active treatment program of the ICF/MR.

2. DHS must inform the applicant or the applicant's legal representative of any feasible alternatives available under the HCBS waiver, and must give the applicant the choice of either entering a nursing facility or receiving home and community-based services. DHS must also express in writing that without home and community-based services, the applicant would require the level of care provided in an ICFs/MR.

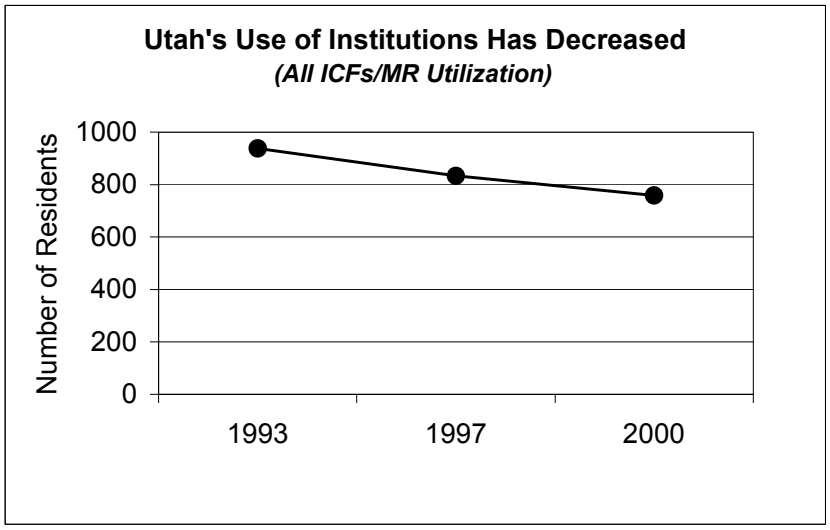
3. The applicant has at least one of the following conditions:
   a) Is severely or profoundly retarded;
   b) Is under six years of age;
   c) Is severely multiply handicapped in that he has at least two of the conditions identified in the definition of mental retardation found in *the Diagnostic and Statistical Manual of Mental Disorders IV, revised 1994*;
   d) More than once per week is physically aggressive or assaultive towards himself or others;
   e) Is a security risk or wanders away at least once per week;
   f) Is diagnosed as severely hyperactive;
   g) Demonstrates psychotic-like behavior; or
   h) Has conditions requiring at least weekly intervention by or under the supervision of a health care professional or trained habilitative personnel.

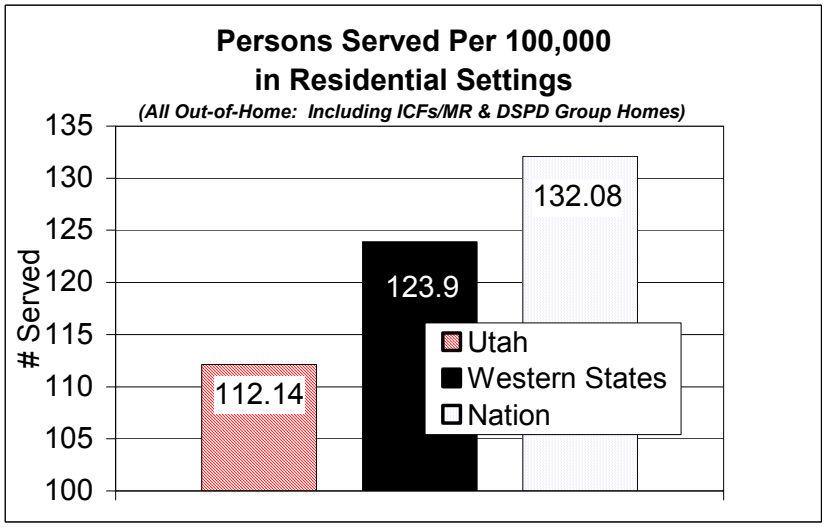
In addition to the Medicaid criteria for admission to ICFs/MR, DSPD conducts a specialized internal review of any children aged 11 and under.

Pursuant to federal and state regulation, facilities provide 24-hour medical services including nursing care, dietary services, assisted daily living and comprehensive care planning on a statewide basis.

Utah State Developmental Center (USDC)

Like providers of community-based services, USDC is currently working to support and promote more person-centered services, a greater choice of services and supports, and increased opportunities for inclusion of people with disabilities in the community. USDC is also working to provide housing that allows more privacy and that is more typical of single adult living in the community. To that end, five of the residential buildings built in the 1960s and 1980s have been remodeled. The remodeling converted the space of living units that housed eight persons, with bedrooms shared by up to four persons and with meals and laundry services provided from one campus location, to self-contained apartments for up to five individuals with no more than two persons sharing a bedroom. USDC included in its most recent annual budget, a request for funds to complete the remodeling of two additional buildings. Based upon this request and upon the need for long-term planning, the State Building Board initiated a study to determine how to best provide for future needs. This study is scheduled to be completed by the end of 2001.





Utah State Mental Hospital (USH)

USH is a 24-hour inpatient psychiatric facility located on East Center Street in Provo, Utah. The hospital serves people who experience severe and persistent mental illness. The hospital provides active psychiatric treatment services for 384 patients. USH serves all age groups and covers all geographic areas of the state. USH works with 10 mental health centers across the State as part of their continuum of care. All adult and pediatric beds are allocated to the mental health centers based on population. There are 21 buildings with approximately 444,000 square feet of space. The hospital campus covers over 300 acres of property.

Major Client Groups at USH:

- Adult patients over 18 who have severe mental disorders (civil commitment)
- Children and youth (ages 6-18) who require intensive inpatient treatment
- Persons adjudicated and found guilty and mentally ill
- Persons adjudicated and found not guilty by reason of insanity
- Persons found incompetent to proceed
- Person who require a competency, Guilty and Mentally Ill, or Diminished capacity evaluations
- Persons in the custody of the Utah Department of Corrections who have mental disorders

Programs:

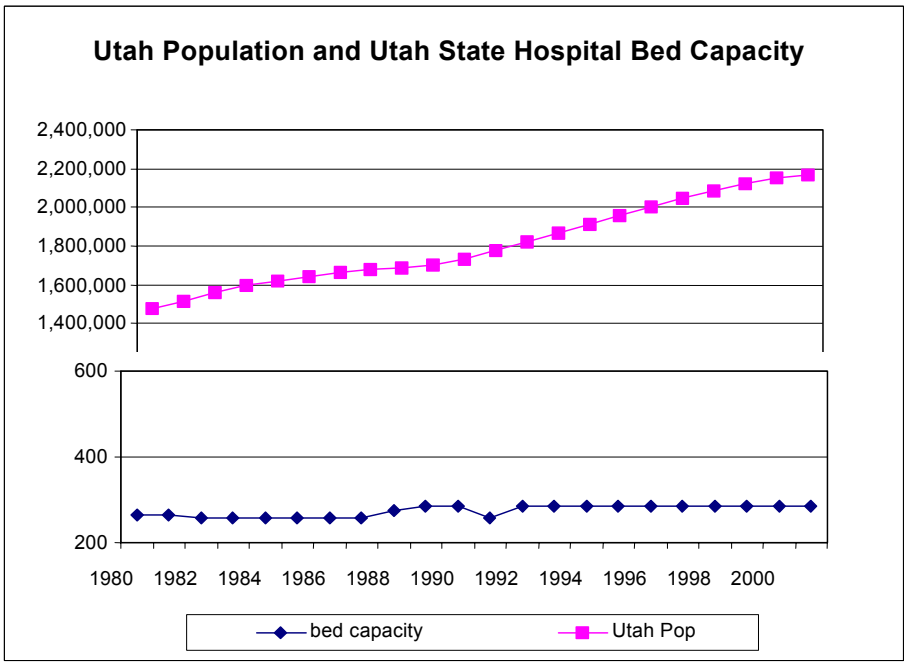
• Children's Unit (Ages 6-12)	22	beds
• Adolescent Unit (Ages 13-17)	50	beds
• Adult Services (Ages 18 and above)	120	beds
• Life Habilitation Unit (Ages 18 and above)	32	beds
• Geriatrics (Ages 60 and above)	60	beds
• Forensic Unit (Ages 18 and above)	100	beds

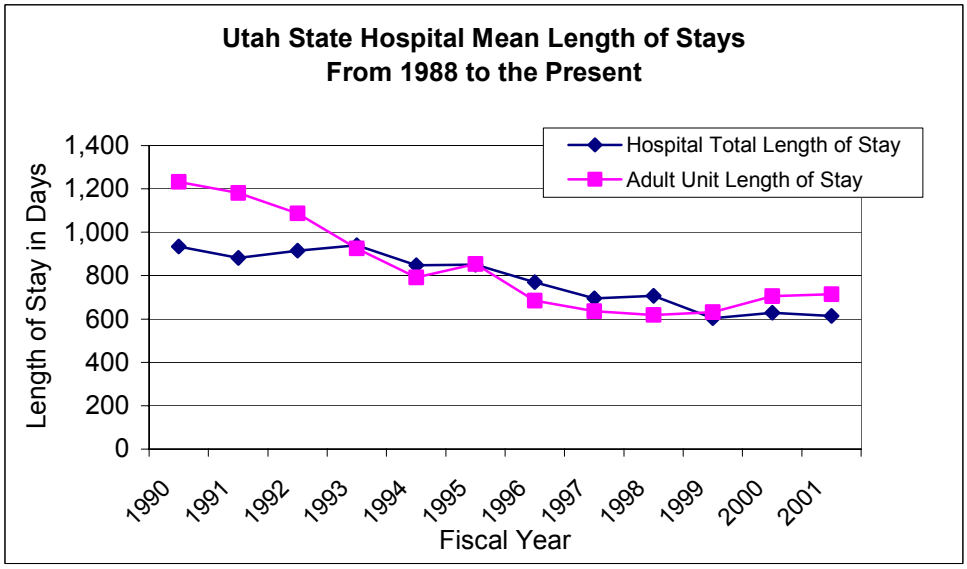
Types of Disorders Treated:

- Psychotic Disorders (schizophrenia, delusional disorder, schizophreniform) = 54%
- Mood Disorders (major depression, bipolar disorder, dysthymia, cyclothymia) = 23%
- Childhood Disorders (autism, attention deficit disorder, conduct disorder, separation anxiety, attachment disorder) = 6%
- Organic Disorders (head injury, Alzheimer's Disease, organic brain syndrome) = 10%
- Other = 7%
- Personality Disorders (borderline, antisocial, paranoid, and narcissistic) - are also treated at the hospital, many times as a secondary diagnosis.

Services provided by the Hospital include: psychiatric services, social work, 24-hour nursing care, occupational, recreational and physical therapy, education programs, and dietetic and medical services.

The graphs below illustrate that while the population and percentage of individuals with mental illness has grown, institutionalized care has not. In addition, the length of stay when an individual is institutionalized, has steadily decreased. Due to continuous improvement and individual clinical reviews, individuals are staying for shorter periods of time before they are transitioned back into the home or community setting. The processes used at USH assist in preventing inappropriate institutionalization.





B. Medicaid Home and Community-Based Services (HCBS) Waivers

The federal government expanded long-term care services in the 1980's by way of Medicaid HCBS waivers. In essence, amendments to the Social Security Act "waived" the requirement that a person reside in a public or private intermediate care facility in order to receive Medicaid funds for services, and allowed those funds and services to extend to eligible persons living with their families or with other persons with disabilities in their home communities. Beginning with the implementation of Utah's first HCBS waiver in 1986, people of all ages with chronic illnesses and disabilities acquired the ability to receive needed services and supports without having to leave their homes and families. This waiver, coupled with the assurance of public education services, gives families of individuals with disabilities a more comprehensive array of alternatives to institutional services. Given the option, the great majority of individuals and families elect to receive services in their own homes, their neighborhood schools, and their local communities throughout their lives. There are currently five HCBS waivers as well as a variety of other state funded services available through the Utah Department of Human Services, the Utah Department of Health and the Divisions within these Departments.

Section 1915(c) HCBS Waiver for Individuals with Physical Disabilities

This waiver provides home and community-based services to individuals whom, but for the provision of such services, would require nursing facility placement. Services provided under this waiver include a local area support coordination liaison, personal emergency response systems (PERS), and personal assistance and consumer preparation. The DSPD administers the Physical Disabilities waiver.

Section 1915(c) HCBS Waiver for Persons with Mental Retardation and other Developmental Disabilities (MR/DD)

This waiver provides home and community-based services to persons whom, but for the provision of such services, would require ICF/MR placement. Services provided include: support coordination, community living supports, personal assistance, personal emergency response systems (PERS), environmental accessibility adaptations, chore and homemaker services, supported employment, site and nonsite based day supports, senior supports, transportation supports, latch key supports, family assistance and support (Family Support), respite care supports, self directed supports, educational supports, specialized medical equipment/supplies/assistive technology and specialized supports. This waiver is administered by DSPD.

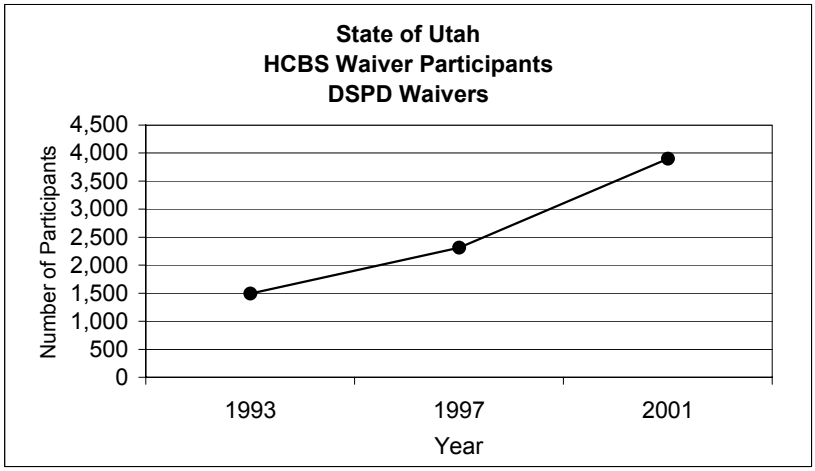
Section 1915(c) HCBS Waiver for Traumatic Brain Injury

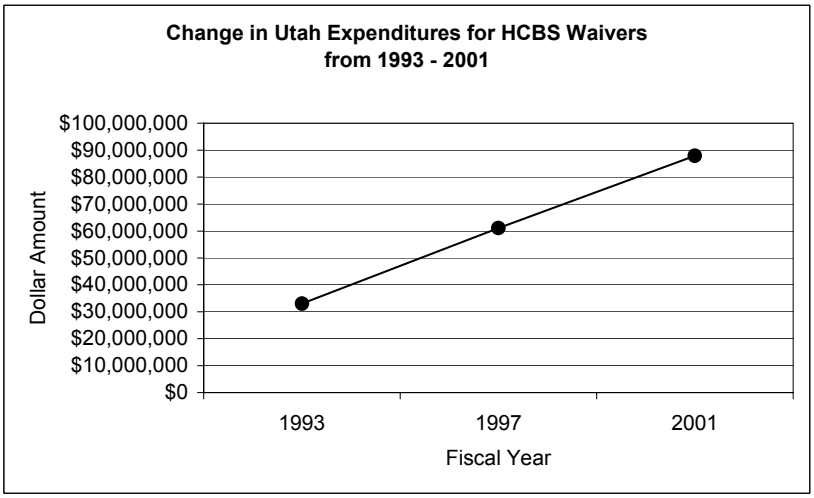
This waiver provides home and community-based services to individuals who but for the provision of these services would require nursing facility placement. This waiver is administered by DSPD. Services are limited to individuals age 18 and older who have a brain injury. Included in this category would be individuals with a cerebral vascular accident. Those who have traumatic brain injury with a primary diagnosis of substance abuse or those with deteriorating diseases such as multiple sclerosis, muscular dystrophy, Huntington's chorea, ataxia or cancer would not be included in this waiver.

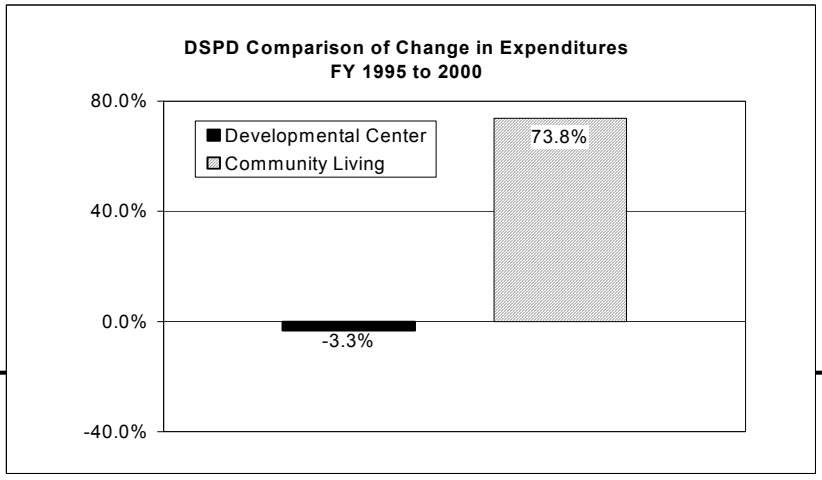
Services provided under this waiver include support coordination, homemaker services, respite care, habilitation, supported employment services, environmental accessibility adaptations, specialized medical equipment and supplies, chore services, personal emergency response systems, companion services, family training, structured day program, community supported living, counseling, behavioral programming, and rehabilitation therapies. This waiver is also administered by DSPD.

The following graphs reflect the changes in participation and expenditures in home and community based services for the disabled population traditionally served by the Division

of Services for People with Disabilities. These graphs show the increase in HCBS waivers over the last seven years.





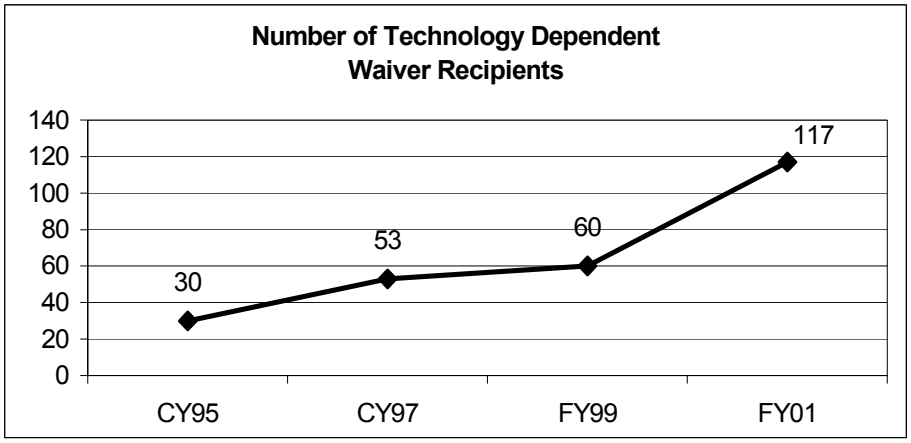


Section 1915(c) HCBS Waiver for Technology Dependent

The purpose of this waiver is to provide a unique array of home and community-based services to a limited number of eligible individuals who would otherwise require placement in a nursing facility. To qualify for acceptance in this waiver, individuals must: be under 21 years of age at the time of admission, meet the level of care criteria for nursing facilities, have at least one caregiver trained and available to provide care, and choose to receive home and community-based services instead of care in a nursing facility. In addition, the individual must require skilled nursing and/or skilled rehabilitation services at least 5 days per week, and must be dependent on one or more of the following:

- a mechanical ventilator
- tracheotomy based respiratory support
- continuous positive airway pressure (C-PAP)
- intravenous administration of nutritional substance or medication through a central line.

DOH's Division of Community and Family Health Services administers this waiver. The services under this waiver are dependent upon a natural support system. The services provided, in addition to traditional Medicaid benefits, are case management, respite care, in-home respiratory care, nutritional evaluation and in-home-based treatment, in-home family counseling and portable oxygen for non-medical transportation.



Section 1915(c) HCBS Waiver for Aging

Individuals age 65 and over who meet nursing facility admission criteria but do not want to reside in a nursing facility are eligible for this waiver. Services provided under this waiver include homemaker, home health aide, emergency response, adult day care,

respite and transportation services, as well as home-delivered meals. This waiver is administered by DAAS. In FY2000, Utah's Home and Community-Based Services Aging waiver served 780 elderly Utahns, enabling them to continue residing in their own homes rather than being placed in long-term care facilities.

C. Other Programs

The Division of Aging and Adult Services (DAAS)

In addition to the HCBS waiver, DAAS provides a variety of services within the long-term care system. Listed below are descriptions of several popular state-funded programs that are home and community-based. For a complete listing of services available, please contact the Division.

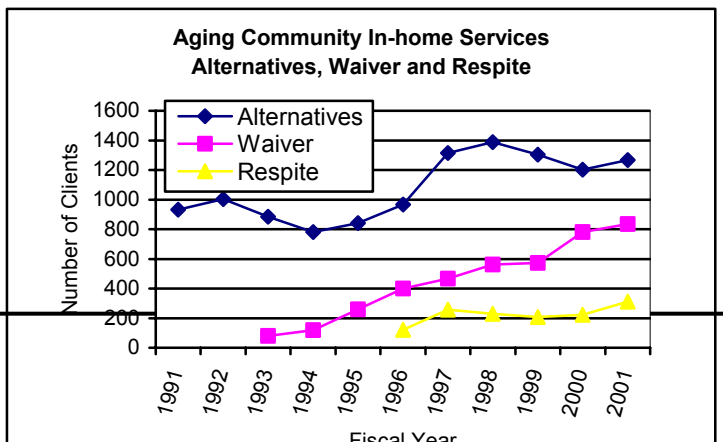
The Alternative to Nursing Home Program (TAP)

Services provided within this program enable individuals who have health, mobility or functional limitations and are at risk for nursing facility placement, to remain in a home or community setting. This program is offered to individuals age 18 and above, although the majority of those served are those age 60 and above. Services provided are homemaker, personal care, home health aide, nursing, respite, home delivered meals, adult day care and transportation. TAP served 1,203 elderly Utahns in FY2000.

Caregiver Respite Program

Providing care to frail, sick or incapacitated elderly is a very demanding activity, which, when combined with other activities in the caregiver's life, can be exhausting and sometimes even affect the caregiver's physical and emotional health. This program provides intermittent and short-term services to allow caregivers a short break from the day-to-day demands of providing care to a loved one. Services include adult day care, homemaker, home health aide, short-term institutional placement, and the use of medical equipment and supplies. The Caregiver Respite program served 223 elderly Utahns in FY2000.

The graph below illustrates the number of individuals served in the three program areas, specifically the Alternatives to Nursing Home, Aging Waiver and Caregiver Respite, from 1990 through 2000. Note: the decrease in numbers for the Alternatives program reflects the movement of dollars from Alternatives into the Waiver.



The Division of Services for People with Disabilities (DSPD)

Individuals with disabilities who qualify for services within the Division may receive community living support, family support, supported employment, supported living, and support coordination case management services. These services may be funded through waivers or general funds. The following table shows the numbers of individuals who currently receive HCBS through DSPD, an agency under the umbrella of DHS:

Persons Receiving Supports
in Most Appropriate Integrated Settings Statewide
by Region and Service Type

Area	Community Living Supports	Day Supports	Family Supports	Supported Employment	Supported Living
Statewide	1,045	1,306	1,086	850	531
Central	501	529	331	288	139
Eastern	60	71	115	19	56
Northern	206	433	341	209	149
Western	278	273	299	334	187

Source: August 2001 Division Access Database Statewide Authorization List

- Community living support includes intensive to intermittent supports in residences ranging from 8 person group homes to professional parent homes or the person's own apartment or condominium.
- Family Support provides assistance to parents and family members to care for their disabled child in their own home.
- Supported Living includes supports provided in the person's own home, apartment or condominium.
- In total there are 3,467 persons with developmental disabilities and/or mental retardation (DD/MR) receiving services in the most integrated, least restrictive setting.
- Most people receive 2 or more types of supports.

The Division of Mental Health (DMH)

In Utah, the delivery of mental health services in the community is the responsibility of the local mental health authorities. Local mental health authorities are the individual county boards. Counties can collaborate in the delivery of mental health services by entering into inter-local agreements with other counties. Public mental health services are funded by all levels of government: federal, state, and county. Counties are required by law to match 20% of the state funds they receive. Counties can provide for the service themselves, or contract with another agency to provide the service. In Utah, there are ten local mental health centers serving one or more counties, as listed in the following chart.

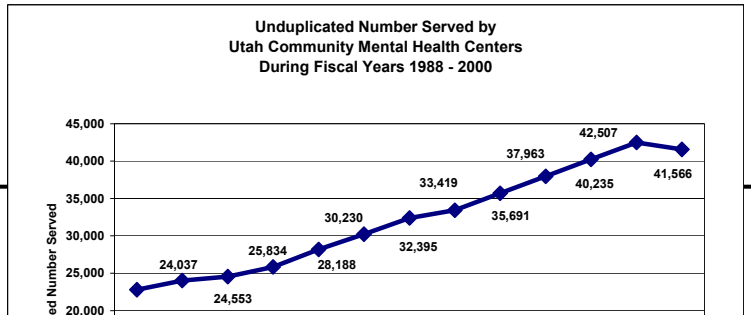
Center	Counties Served
Bear River Mental Health	Box Elder, Cache, and Rich
Davis Behavioral Health	Davis
Weber Mental Health	Weber
Valley Mental Health	Salt Lake, Summit, and Tooele
Northeastern Counseling	Daggett, Duchesne, and Uintah
Four Corners Mental Health	Carbon, Emery and Grand
Wasatch Mental Health	Utah and Wasatch
San Juan Mental Health	San Juan
Southwest Center	Beaver, Garfield, Iron, Kane and Washington
Central Utah Mental Health	Piute, Sevier, Juab, Wayne, Millard, and Sanpete

All local authorities and their contractors are accountable to the Department of Human Services and the Department of Health with regard to their use of state and federal funds. DMH provides monitoring and oversight for the ten local centers. The local authorities are responsible for reviewing and evaluating mental health needs and services, and are required to submit an annual plan to the Division for the funding and delivery of required services. These mandated services are:

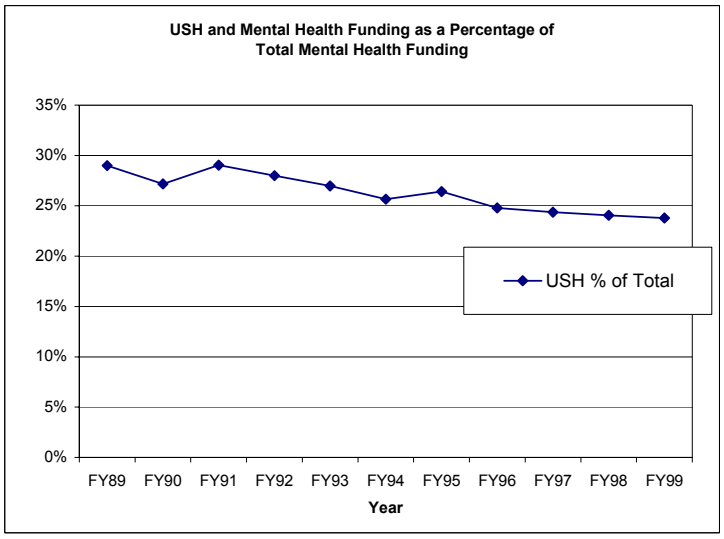
- Inpatient care and services.
- Residential care and services.
- Outpatient care and services.
- Twenty-four hour crisis care and services.
- Psychotropic medication management.
- Psychosocial rehabilitation including vocational training and skills development.
- Case management.
- Community supports including in-home services, housing, family support services, and respite services.
- Consultation and education services, including but not limited to case consultation, collaboration with other service agencies, public education, and public information.

Additional services provided by many of the mental health centers include the clubhouse model for rehabilitation and integration of mentally ill adults, consumer drop-in centers, services to homeless individuals, forensic evaluations, nursing home and hospital alternatives, and consumer and family education. Many of the centers also provide public education and prevention programs.

Many of the smaller counties are combined local mental health and substance abuse treatment centers. As such, they provide not only mental health treatment, but substance abuse treatment and prevention programming as well.



The graph above shows that the number of individuals served has dramatically increased each year through 1999. At the same time, funding for mental health has remained fairly static. The graph below shows that the percentage of funding for the Utah State Hospital has decreased as compared to the overall mental health funding.



D. Home and Community-Based Special Initiatives

Portability

In 1998, the Utah Legislature enacted the *Portability of Funding for Health and Human Services* law, which mandated the review of services for persons with disabilities in ICFs/MR and community-based residential services. In April 1999, DSPD, within the Utah Department of Human Services, and DHCF, within the Utah Department of Health, initiated an annual open enrollment process to provide a choice to individuals receiving publicly funded services in ICFs/MR and the DD/MR Waiver. This open enrollment process is referred to as the "Portability Project", as the funds to support the individuals are "portable" between the two participating Divisions. Supporters of this project, who assist in the coordination of services, include the Utah Health Care Association, ICFs/MR facilities, the Disability Law Center, the ARC of Utah, the Legislative Coalition for People with Disabilities, the Governor's Council for People with Disabilities and consumers.

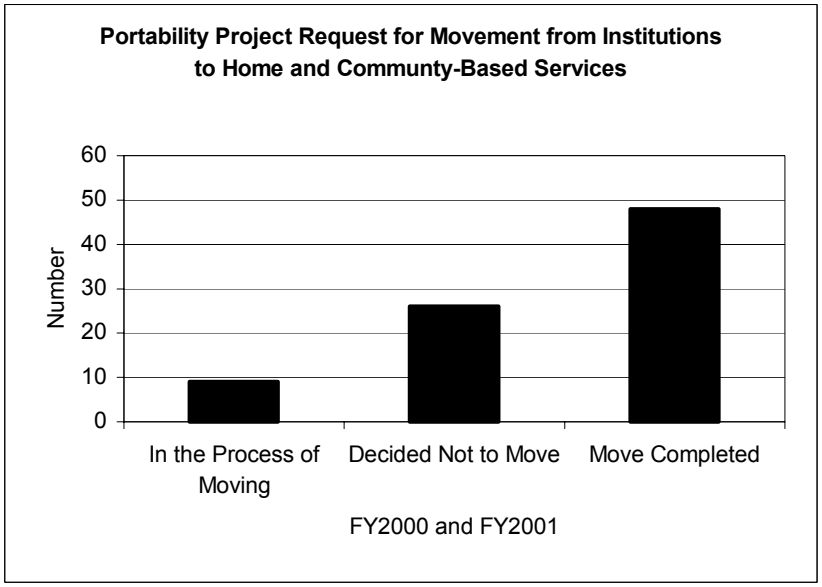
Under this process, during an open enrollment period each year, persons in both programs can initiate a transition evaluation and planning process to determine whether transfer between programs is feasible within established parameters and to coordinate the transfer when appropriate. The evaluation and selection of alternative arrangements is accomplished through a cooperative effort of the individual receiving services, Division of Services for People with Disabilities staff, and others selected by the individual. To date the Portability Project has proven successful in creating an open atmosphere of choice for the individuals that are served through these two programs. Below are some of the key results achieved in fiscal years 2000 and 2001. Fiscal year 2002 activities are currently underway, however the results are not yet available for report or comparison.

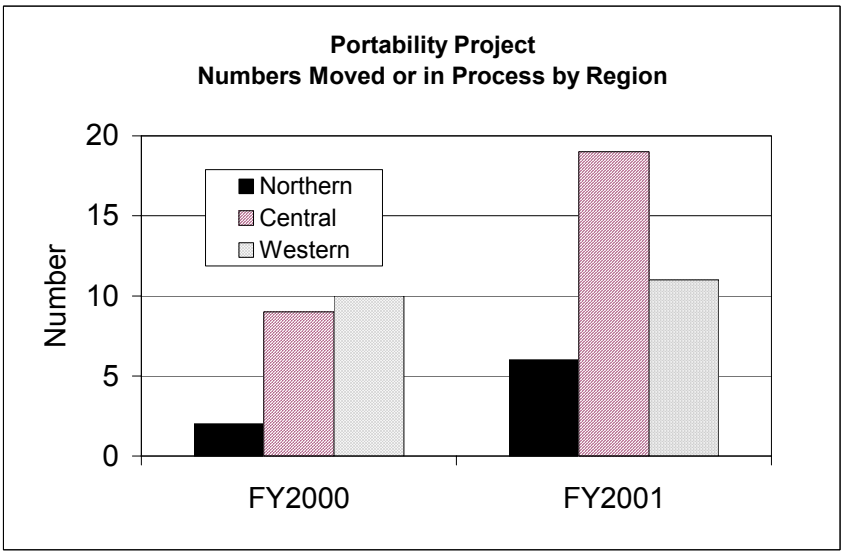
The outcomes from this process are:
In order for portability to be successful, it is imperative that the moves remain budget neutral, in the aggregate, with no overall increased cost incurred by the two Divisions. For FY 2000, budget neutrality was maintained with an average daily per person expenditure of $119.00 for those persons who transferred between programs. For FY 2001, partial data collected at this time indicate annual savings of at least $5,000.00 per person will be achieved for those persons who transferred between programs.

Through the Portability Project individuals have been able to choose the setting in which they live and receive services and supports, thereby enhancing their ability to have control of their lives. These individuals have integrated into the local social community and the work setting. Satisfaction surveys are currently being completed to measure performance of the Project from the individuals' perspectives.

Project Statistics: FY2000 and FY2001:
The following charts provide details of the Project. For FY2000 and FY2001, a total of 83 requests to transfer to the DD/MR HCBS Waiver program were made. Of those requests, 48 have been completed, nine (9) are in process of

transferring, and 26 decided not to transfer after making their initial request. There were no requests made to move from the DD/MR HCBS Waiver program to an ICFs/MR.





Flex Care Program

Overview and Outcomes:

The Long-Term Care Demonstration Project (FlexCare) is a three-year demonstration project initiated by the Utah Department of Health in April of 2000. The project is designed to enable the State to gain experience in transitioning an appropriate segment of the Medicaid nursing facility population into a home setting or other appropriate community-based setting through the use of individualized case management and a flexible array of services and supports. FlexCare seeks to develop an integrated and comprehensive array of long-term care services that provide optimal quality to eligible individuals in the most integrated and cost-effective setting. Results from the demonstration project will

be used to shape future public policy and service models for long-term care in the State of Utah.

FlexCare will serve up to 500 Medicaid recipients at any given time during the 3-year period and is initially limited to individuals residing in Davis and Salt Lake County. Qualified Medicaid recipients who voluntarily select the FlexCare project, including the accompanying Medicaid HMO, will receive primary and acute care services and an expanded array of long term care services through this arrangement.

The FlexCare consortium, made up of United HealthCare of Utah, Valley Mental Health, and Superior Care Pharmacy, is working with the Department of Health as the selected contractor to implement the demonstration project. The Department pays FlexCare a daily long term care per capita premium for each enrollee in the demonstration project in addition to the HMO per capita premium paid to United HealthCare of Utah for acute and primary care services. The FlexCare consortium is then responsible for developing a comprehensive care plan for the enrollee and managing its implementation. Superior Care Pharmacy's primary role is to provide technical assistance in managing the drug regime of the enrollees.

Current Utilization:

The project is on target to meet its enrollment goals. As of October 2001 there are 145 clients currently enrolled in the FlexCare Project. There are approximately 50 inquires to the project each month about the project of which approximately one half are potentially eligible and become formal referrals to the program. To be eligible for the program an applicant must: (1) be currently on Medicaid or determined to be Medicaid eligible; (2) be either a resident in a nursing home with a determined long-term care need, or be in a hospital setting with a discharge plan to a nursing home on a long term stay; and (3) be over the age of 18. As shown in Table 1, the average age of the FlexCare clients is 65, with 52% of the clients being between 51 and 70 years of age. One goal of the program is to transition clients to the least restrictive and most cost-effective setting. To this end, as shown in Table 2, 62% have transitioned to assisted living facilities and 14% of clients have returned home. The most common services utilized are home health (65%) and mental health services (33%).

Table 1

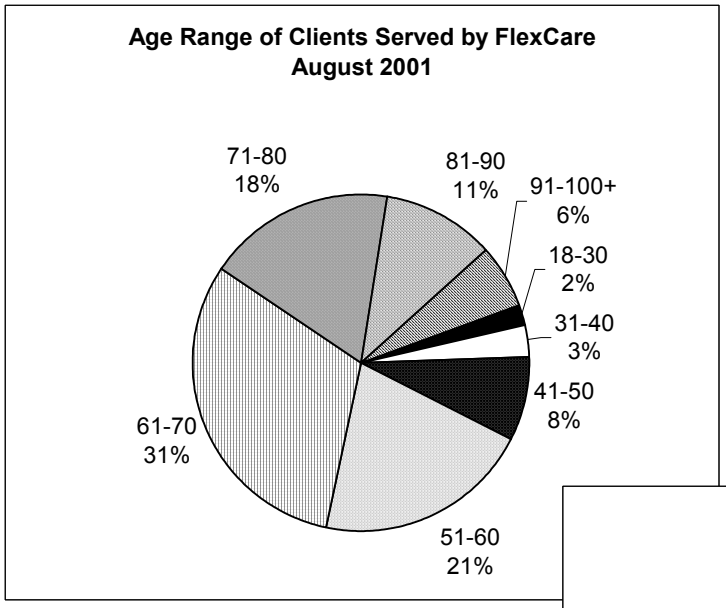
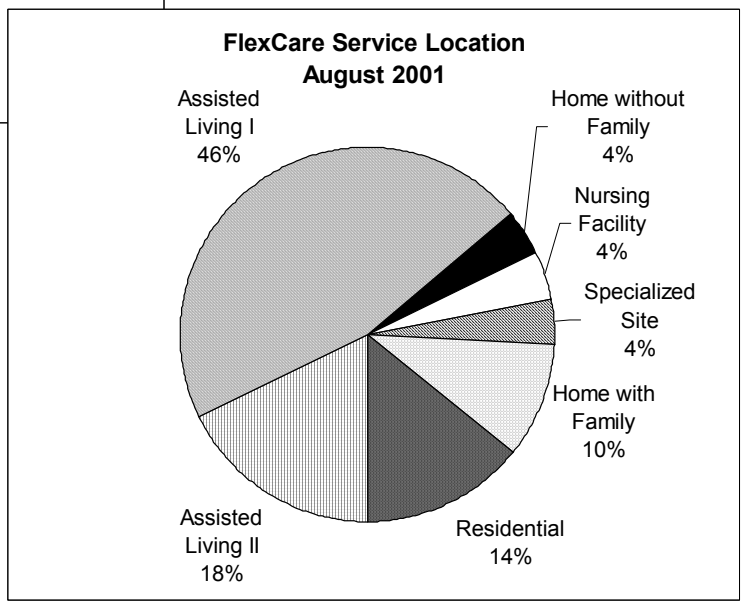
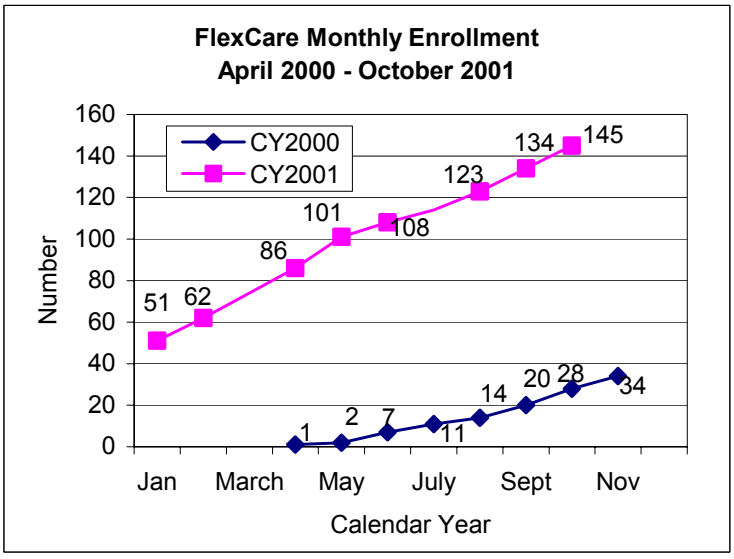


Table 2





Cost Neutrality:
Assuring cost neutrality is critical to this project. Financial data continues to be tracked monthly. Cost neutrality is determined on an aggregate basis using the average daily rate paid to nursing facilities by Medicaid. Of the 101 individuals placed through the end of May, four (4) clients cost more than the average daily nursing rate, 20 clients were essentially revenue neutral and 77 cost less. Experience so far suggests that costs decrease for individual clients as they stabilize in their home or community-based placements.

Quality Assurance:
The Division of Health Care Financing monitors the quality of the FlexCare program and makes recommendations for program improvement to the contractor. In addition, the Social Research Institute at the University of Utah is performing a quality of life evaluation study to measure project performance from the enrollees' perspective.

ADA *Olmstead* Planning Grant Nursing Home Resident Education Project

Through a planning grant from the Center for Health Care Strategies, the Utah Division of Health Care Financing (DHCF) conducted an educational campaign using community-based organizations (local Independent Living Centers and Area Agencies on Aging (AAA's)) to conduct on-site education of nursing home residents. The two primary objectives of the project were: 1) to develop processes and resource bases which will enable, to the greatest degree possible, individual Medicaid consumers and their support networks to access needed services and supports in the setting of their choice; and 2) to inform the Utah Departments of Health and Human Services regarding gaps in the long term care continuum.

The DHCF began implementing the education process by first educating interested individuals currently living in nursing homes. DHCF chose these individuals as the target population for education and outreach because of the perception that some residents may have been placed in a nursing home without knowing or understanding all of their options. The education process consisted of three steps. First, the contractors conducted group educational sessions at each nursing home in the state. The contractors gave presentations, distributed information packets, and met with facility administrators and social workers. Second, the educators provided one-on-one education sessions with interested residents to answer individual questions and discuss options in more detail. Third, an assessment team consisting of a Licensed Registered Nurse and a Licensed Social Worker or Mental Health Therapist conducted intensive needs assessment for interested clients to identify services and supports necessary to meet the needs of the client in a community based-setting. The client was provided with the results of the assessment and related program referral information.

Utah Medicaid Redesign Project Dual Diagnosis Pilot

The State of Utah is currently implementing a pilot program now known as Habilitative Options and Medical Excellence (HOME), that provides comprehensive health care management to individuals with mental retardation and mental illness. This is an innovative approach that manages and coordinates the consumer's medical care, mental

health treatment and wrap-around services. Historically, these services have been delivered through separate systems with little, if any, communication among service providers.

The purpose of this pilot is to improve quality and cost effectiveness of service delivery for a population of individuals with a dual diagnosis of mental retardation and mental illness. In this pilot we have integrated Medicaid services, normally provided through multiple entities, under a single managed care option. The target population for the pilot includes children and adults with dual diagnosis who live in Salt Lake County. To participate, individuals must be in the DD/MR waiver and choose to be enrolled in the pilot. The total enrollment in the pilot is limited to 100 individuals until we can validate the quality and cost effectiveness of care.

The University of Utah Neuropsychiartic Institute is the single service provider. Administration of the pilot is through the University of Utah, Health "U". Enrollment began in August 2000 and there are currently more than 60 individuals served in this pilot.

The Dual Diagnosis pilot includes the following components: 1) inclusion of self determination principles and procedures (i.e. person-centered planning) so that health care and community support providers will respect and support the individual with disabilities as the decision maker; 2) development of a provider network of primary and specialty providers (including physical health, mental health and long term support providers) for effective diagnosis, treatment and support of the enrollees; 3) development and use of a management information system to track encounter data, outcomes and costs to be used in subsequent rate setting; 4) development of best practice standards to serve the population; and 5) a process to review data to further assess the effectiveness and need for expansion of a dual diagnosis HMO.

The Care Coordination Team is the driving force behind this medical home and coordinated care model, and consists of a registered nurse, a licensed clinical social worker and a Division of Services for People with Disabilities' support coordinator. Mental health services that had been difficult to access for many of the participants are being provided under this model. The team has worked with medical professionals to design a template for a comprehensive, coordinated treatment plan that will be used as a tool for the project. It is in the final stages of development and integration into the information technology system.

Outcome measures are being tracked and data organized to be able to show which interventions are successful and meaningful for the individuals as well as the overall group. Data collection for long range research on the project is under way. This data will provide valuable information about consumer satisfaction, and will be evaluated for its success in ensuring that the appropriate level of treatment is provided.

Frontiers Project Grant

The Frontier's Grant is a seven-year pilot to build a statewide system of care for children and youth with serious emotional disorders and their families. The project began in 1997 and has two rural pilot sites. The system of care services utilize natural supports and involve all the agencies and organizations in a community that serve kids through

effective collaboration. Key components of a functional system of care are family involvement and self-advocacy.

Data reflect that the children being served in the two pilot sites are children that have multiple needs, including mental health, poverty, and substance abuse issues. By utilizing a variety of interventions, providers are able to offer services within the home and/or community, thus preventing institutionalization.

The goal of this project is to develop a model for "wrap-around" services. The total number of children served in the two pilot sites from August 1998 through October 2001 is 76.

E. Other Supportive Services

State of Utah Housing Programs

Housing programs administered by the State of Utah fall under either the Housing Corporation, which adminsters tax credit programs, or the Olene Walker Housing Trust Fund. The Olene Walker Housing Trust Fund is composed of state and federal funds that assist in the construction, rehabilitation, and purchase of multi-family and single-family housing throughout Utah.

To qualify for assistance by the Fund, Utahns must first demonstrate that they make 80% or less of the area median income. The Fund is targeted toward those who have the lowest incomes such as the elderly, mentally and physically disabled, victims of domestic abuse, homeless, etc. Lower income first time homebuyers qualify for assistance as do lower income homeowners. All assistance is given to persons without regard to their ethnicity.

Money from the Fund is usually given as a loan to individual homebuyers or home-owners, or to affordable housing developers including both for-profit and non-profit agencies. The money is then managed as a revolving loan fund. As the loans are returned to the fund they can then be used on future projects. On going efforts are made to form partnerships with lending institutions, communities, non-profit agencies, developers, community groups and others to create affordable housing. Trust Fund resources are also used to fill gaps in funding to make worthwhile projects work financially by subsidizing the costs to make the project feasible.

Through Olene Walker Housing Trust Fund partnerships during FY1999, 739 units of multi-family affordable housing were created and 66 units of single-family affordable housing were rehabilitated or created.

In addition, the Housing and Urban Development (HUD) federal agency funds a significant amount of housing projects each year. Locally administered Housing Authorities operate subsidized housing statewide.

Transportation

The size and geographic diversity of Utah makes transportation a critical element in the delivery of human services. Along the Wasatch Front, the Utah Transit Authority (UTA) provides public transportation utilizing buses, light rail (TRAX) and the flex-trans system. Additionally, some counties provide smaller scale public bus systems (e.g. Park City within Summit County and St. George within Washington County).

Medicaid recipients in need of medically related transportation are served by a statewide contract.

Medicaid pays for non-emergency transportation to medical providers when there is no other appropriate public or personal transportation available (e.g., doctors, dentists, and outpatient services).

DAAS, through contracts with local government, assists in the provision of transportation assistance for medical and non-medical related trips for the elderly. Access to reliable, affordable transportation is probably one of the most important services needed by a senior to remain independent. Having relinquished their license to drive a private vehicle because of the onset of functional limitations, often incidental to aging, access to transportation for medical appointments, shopping, and to senior centers is of vital importance. Public transportation is most often restricted to the urban areas of the state and is more directed to the needs of a younger employed population. Transportation service provided by the local AAA's is available, but because of funding limitations is most often limited to transporting seniors to senior centers. Transportation for medical appointments, shopping and other normal functions of independent living is often restricted to those in greatest need. Lack of adequate transportation can lead to social isolation that can result in depression and the need for medical attention. Assisting the senior population in meeting their transportation needs continues to be a high priority for the AAA's.

Workforce Services

The Department of Workforce Services (DWS) is a consolidation of all workforce functions, including what was formerly known as welfare, into one service delivery system. This simplified system provides employment exchange services for both employers and job seekers. The core function of the agency is employment exchange. All other services support this function. The entire array of services are available at any of the 50 employment centers statewide. Services are categorized in three areas: services to the job seeker, services to the employer and supportive services.

DWS is the public employment agency for the citizens of Utah. DWS tracks labor market information such as market trends and labor shortages or surpluses. DWS also provides job training and public assistance for the poor, aged and disabled. These services are a critical element in the overall effort to reduce the gaps in infrastructure and services. By providing these services, DWS seeks to remove barriers to the transitioning of qualified individuals from institutions to home and community-based settings.

V. SUMMARY

Over the last several years, the allocation of public funds has moved dramatically toward the provision of services in non-institutional programs. The Utah State Legislature has increased funding to provide additional community services for waiver populations. While this has not always resulted in shorter waiting lists, there has been a significant increase in the number of people served in community settings as well as a significant increase in the percentage of the State Medicaid budget going to community-based services.

Medicaid continues to be the primary payor of publicly funded long term care services and, therefore, serves as a strong barometer of the progress made in providing least restrictive, most appropriate services.

In addition to shifting the balance of Medicaid expenditures, Utah has taken the following steps in support of community based services:

- The Department of Health implemented a moratorium affecting new nursing facilities and ICFs/MR beds in 1989, in order to limit the growth in the number of institutional beds eligible for Medicaid reimbursement. Current nursing facility occupancy stands at 74%.

- The State of Utah has not allocated resources to fund growth in the ICFs/MR budget for the past ten years. Resources that would normally be used for the ICFs/MR budget have been diverted to fund individuals who are in a home or community setting and who are in crisis and have no other funding. This service is called the Emergency Services Management Fund. A committee comprised of Division of Services for People with Disabilties staff, a private ICFs/MR representative, a consumer or family advocacy organization, a consumer, and a family representative determines the priority use of the Fund based on the following risk factors:

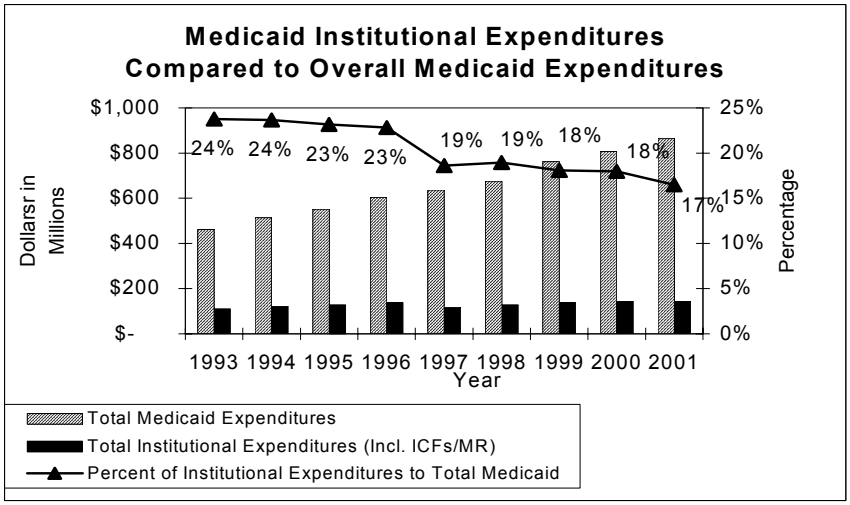
  - Immediate threat to health or safety;
  - Immediate risk of becoming homeless;
  - Immediate risk to a child who can no longer be maintained in his or her family residence;
  - Immediate threat of causing injury to others or property destruction;
  - Immediate risk of losing one's caregiver or deterioration of one's family; and
  - Immediate need of a less restrictive place to live (for example a USDC resident no longer needing that level of supervision).

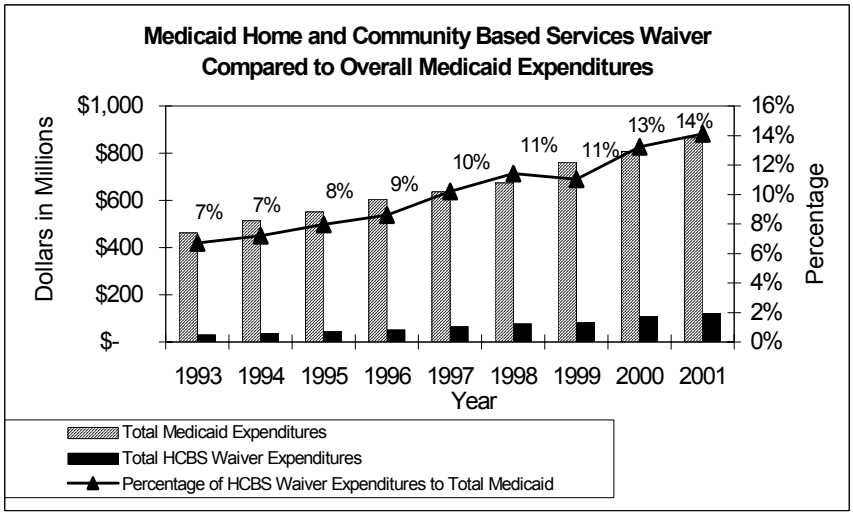
In most other Medicaid programs there have been annual increases for growth, driven by an increase in the number of individuals served.

Together, these steps have enabled Utah to make significant progress in closing the gap between Medicaid expenditures for institutional care and for home and community-based care. The charts below illustrate the results of this gap-closing. The charts also reflect Medicaid expenditures for all recipients across the long-term care system including those with physical disabilities, age related functional disabilities, mental retardation, developmental disabilities, and/or mental illness. Not included in these charts are programs serving the same populations that are funded exclusively with state

general funds, and those programs with other federal funding sources such as the Older Americans Act that also assist in maintaining individuals in the community.

Public Expenditures for Long Term Care Services





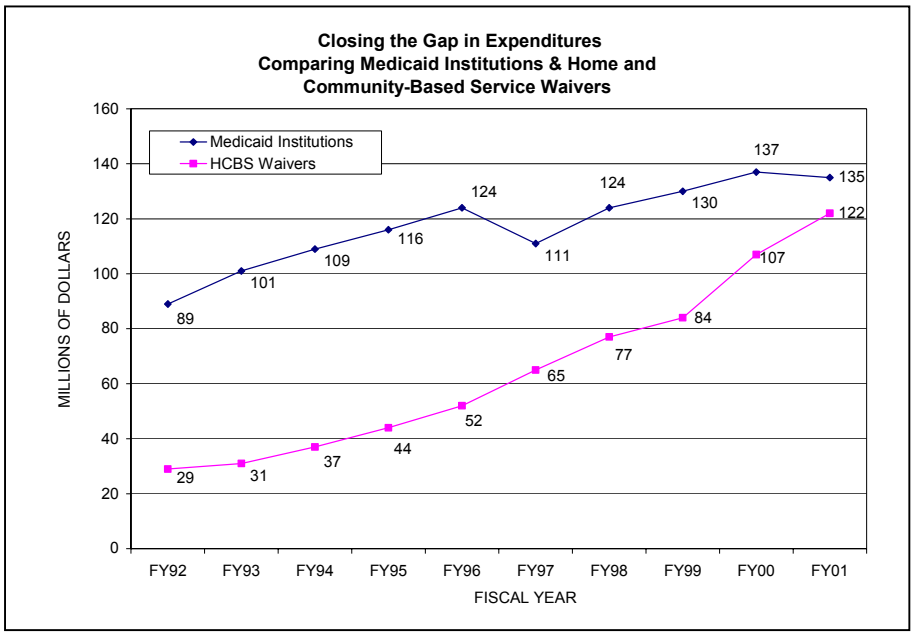
Other examples of closing the gap are:

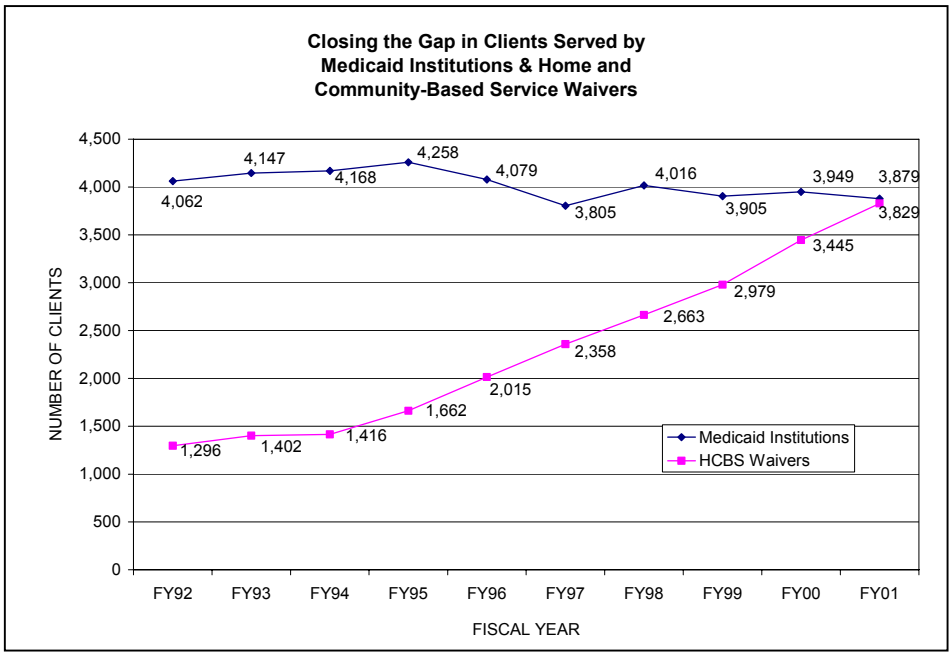
- The Utah State Hospital has aggressively moved to shorten the average length of stay and has moved more qualified recipients into community-based care.

- DHCF home health nursing home diversion services have been in place for several years. While this program has not had a large number of recipients, it has diverted some individuals from a nursing facility placement to a residential setting. This program pays a home health agency a flat monthly rate to provide needed home health and personal care services to an individual recipient.

- The *Lisa P.* settlement prompted the movement of those who need community-based services out of the USDC and into the community.

- Through a planning grant from the Center for Health Care Strategies, the Utah Division of Health Care Financing (DHCF) has undertaken a strategic effort to enable, to the greatest degree possible, individual Medicaid recipients to access needed services and supports in the setting of their choice. DHCF intends to use this process to increase the ability of Medicaid recipients and their support networks to obtain complete information about available long-term care programs at an appropriate time. Clients should be able to make informed choices at any point during their involvement in the long-term care system.





A. Barriers

During our efforts to enhance community-based services, advocates, consumers and agencies have been continually working to identify barriers and gaps in the overall long term care system. The Physical Disabilities and DD/MR workgroups, which are subgroups of the overall Olmstead Comprehensive Plan Advisory Group, identified the following barriers and needs:

- availability of dependable support to complete daily living activities (non-agency, non-professionals)
- transportation variations across the state
- flexible medical services to cover what was available in institutional settings on 24 a hour basis
- information to individuals on long term care options and choices at the right time and in the right format
- strong behavioral and mental health supports in the community for (both self-injurious and acting out)
- neurological supports in the community
- lack of specialized training for mental health providers in dealing with DD/MR clients
- gap in paying for psychological evaluations for non-Medicaid adults
- physical, occupational, speech therapy
- hydrotherapy
- pharmacy services, i.e. drug regime planning
- professional parents that properly fit individual
- after school and summer programs for under 11 age groups
- assistance with changing over government services from institution to community
- special services to support professional parents (therapies)
- dental services for specialized populations
- access to community professionals since many do not want to accept Medicaid
- specialty providers for special populations, i.e. CP, CT, Autism
- transition to home or community living costs
- ready access to sufficient client base for new providers (RFP system)
- adequate orientation and training for new providers on how to work in Utah's system
- lag time between delivering services and payment for those first starting up
- Specific rural factors;
    - Accommodation for provider travel distances
    - Lack of provider choice
    - Lack of specialty care, i.e. psychiatric, neurological
    - Transportation
    - Accommodation for special population with low incidence of condition/disability

The Housing Workgroup which is a subgroup of the overall Olmstead Comprehensive Plan Advisory Group identified the following barriers and needs:

- Characteristics that impact the type of housing needed by persons with disabilities
    - Level of mobility (wheelchair, walker, independent)
    - Level of motor coordination (ability to maneuver through narrow spaces
    - Level of sensory perception (hearing impaired, visually impaired)
    - Level of cognitive ability (independent to 24-hour monitoring)
    - Level of physical assistance required (independent to 24-hour care)
    - Number of sleeping units needed (single occupant to large family)

- Financial arrangement desired (home ownership, lease, rental)
- Social settings desired (single residence, shared housing, small congregate housing, large congregate housing)
- Length of time housing is needed (temporary versus permanent)
- Multiple categories of disability (physical, cognitive, mental illness)
- Family arrangement (parents living together versus separated with two housing units)
- Level of reliance on public transportation
- Ability to use modified public stock versus need for total specialized design

- Major topics to be addressed
  - What to build (need an array of options)
  - How to educate (developers, financing agencies, politicians, consumers)
  - How to market
  - How to maintain current stock (maintenance and repair, loss to other uses)
  - How to overcome discriminatory practices (no wheelchairs, wheelchairs only, elderly only, visible impairment only, total impairment)
  - How to supplement added construction costs directly related to accessibility
  - How to supplement rent/mortgage for low income persons

- Specific design problems for persons with physical disabilities
  - Wheelchair accessible buildings (door widths, lower cabinets and appliances, large bathrooms and kitchens (turnaround space)
  - Apartments on ground level
  - Protection from damage by wheelchairs (edge protectors, carpet on lower walls)
  - Wall outlets higher on walls
  - Low pile carpet
  - Dials on front of appliances
  - Strobe and audible signaling life-safety devices
  - Laundry facilities within unit
  - Remote control door locks and opening devices
  - Access to external amenities
  - Access to common laundry facilities
  - Covered porches
  - Length of porches
  - Accessible parking stalls
  - Parking for service providers (health agencies, Meals-on-Wheels)
  - Flex Trans and school bus access and curbside parking
  - Access to complex if gated (individual, service providers, transportation)
  - Carport accessibility for high-top vans

The Aging Network (comprised of the State Division of Aging and Adult Services and the twelve Areas of Aging throughout the state) and individuals with experience in the delivery of home based community care in October 2000, identified barriers and needs in the following areas:

- education,
- access to information,
- coordination of services,
- transitional resources,
- housing,

- medical care,
- abuse, neglect and exploitation.

Continual discussion in the Olmstead Comprehensive Plan Advisory Committee includes many of the issues identified above. The barriers identified in this document apply broadly and do not necessarily fit the narrow scope of the *Olmstead* case. Many of these barriers are a result of the general lack of available resources in all program areas.

Often times in discussions among public agencies, advocates, and consumers, the issues of waiting lists is raised. There are several waiting lists for services in the community for the aged, for people with disabilities, and for available housing, as well as for other populations and services. These waiting lists are almost entirely comprised of individuals currently in the home or community who are waiting for home and community-based services, not those who are currently in institutions waiting for services. These waiting lists for non-institutionalized individuals are not included in this document, as they are not within the planning process identified by the Olmstead decision.

B. Problem Statement

After a thorough review of Utah's history of institutional services, its efforts to close the gap in the allocation of financing between institutional and home and community based services, the updated statistical results of its various long-term care waivers and initiatives, and continuing discussion by various workgroups of the lingering barriers and needs related to the broad spectrum of publicly funded services, the following specific problems were identified. While these statements can apply to all long-term care services, in fact, all public services, for purposes of this plan, they are narrowed to relate to the specific parameters of the Olmstead decision.

1. Individuals and families often enter the long-term care system without accessing the most appropriate and least restrictive services. This problem exists due to a lack of communication concerning information about the various resources and options available to consumers.

2. Services are created, funded, administered, and delivered categorically thus inhibiting coordination both within organizational units and between different organizational units at the state and local levels.

3. There is currently a lack of sufficient community providers and other workers to meet the demand for services. Often times, even with available funding, there is also a substantial lag time between request and approval for services and the ability for public and private agencies to deliver the services. This lag time is the result of numerous factors including but not limited to having a sufficient provider pool, staff recruitment and retention, and securing housing or other service settings.

Having considered the state's history, current available resources, identification of barriers, and the preceding problem statement, coupled with the responsibility the State has undertaken for the care and treatment of a large and diverse population of persons with mental and physical disabilities, the following section identifies Utah's comprehensive and evolving plan for public services.

VI PLAN FOR COMPREHENSIVE SERVICES

A. Goals

1. The State will continue to make good faith efforts to enable qualified recipients in institutional settings to receive applicable services in a less restrictive environment within five years.

2. Once a qualified individual elects to move to a less restrictive environment and State professional staff agree that such a move is appropriate, the move should occur as fast as reasonably possible given the individual's needs and available supports and funding.

3. Continue the assessment of disabled individuals and their critical needs to determine whether publicly funded home and community-based services are appropriate.

Taking into consideration the barriers, problem statements and goals identified earlier in this document, the state will continue its efforts to meet the increased needs of the diverse disabled population in the most integrated, least restrictive environment.

To assist the State in accomplishing the identified goals, the action plan outlines the course of action to be taken in three categories: overarching home and community based initiatives, cross agency planning and individual Department or Division plans.

B. Home and Community-Based Initiatives Action Plan

- Evaluate the outcomes of the Department of Health's Long Term Care Managed Care Initiative (FlexCare) to determine whether to expand to other areas of the state;
- Outline the plan for continuing the DD/MR Open Enrollment Process (Portability) by reviewing:
    - the progress and outcome data, obtaining additional input from the original design group, and making any necessary modifications to the programs outline.
- Design the plan for continuing the Nursing Facility Consumer Education and Assessment Process and determine the feasibility of implementing the processes over long term by evaluating;
    - assessment data from the current project to determine needs and availability of resources;
- Evaluate the effectiveness of the Dual Diagnosis Demonstration Project and determine the appropriate course of action for continuing, modifying, or expanding the project;
- Design necessary modifications of existing 1915(c) HCBS Waivers to assure compliance with the intent of the January 2000 letter from the HCFA State Medicaid Director;

- Evaluate existing agency policies and practices relating to the current 1915(c) HCBS Waivers to address issues that may exist in terms of both
  - equitable allocation of resources between the various target populations, and
  - equitable access to covered services between the various waivers; and
- Evaluate existing waiting lists to address issues that may exist, and make any necessary modifications.

C. Cross Agency Action Planning

The following apply:

- Design a model for continuity of care across the Long Term Care system, which will include clearly delineated elements of institutional-based services, community congregate care-based services and home-based services;
- Design necessary modifications to existing agency policies and practices to assure an objective, reasonable and consistent methodology for defining and measuring institutional level of care as an element of Long Term Care program eligibility;
- Design a model for integrating long-term care programs into the continuum of care for persons who do not meet institutional level of care eligibility criteria;
- Integrate self-determination concepts into the long-term care system;
- Identify opportunities to expand access to effective services through the redesign and unbundling of existing service packages and definitions (attendant care, personal care, emergency response systems, assistive technology, and environmental adaptations are among the services to be considered.);
- Identify effective approaches to expand access to community-based services by complex populations that cannot currently be appropriately served outside an institutional setting (intensive behavioral characteristics, advanced dementia, heavy assist needs, and intensive skilled, all those who are non-complaint with treatment regimes should be evaluated.);
- Identify the problem, need, and potential partners for expanding the integration and transition of housing and health care for persons with chronic illness and disabilities, as well as the specific desired outcome;
- Identify the problem, need, and potential partners for expanding medical and non-medical transportation for persons with chronic illnesses and disabilities as well as the specific desired outcome;
- Identify the problem, need, and potential partners to support meaningful, integrated employment for persons with chronic illness and disabilities;
- Identify the problem, need, and potential partners to address workforce shortage issues in the long-term care system; and
- Design and implement a system for the sharing of accurate, current and responsive information about the availability of services for persons seeking assistance. To prevent the untimely loss of independence for a disabled person, due to the lack of knowledge of the available options.

D. Individual Department or Division Plans

The state's plan is a compilation of concepts and principles taken from the various reports of each affected agency within the Department of Human Services, the Department of Health and the Department of Workforce Services. As additional action

steps from various agencies or communities are developed, reviewed and approved they will be added to this plan Individual division plans are available from the respective divisions within each department. Some of the goals and recommendations in the divisions' plans are found in the state's plan, while some are not. The comprehensive plan is Utah's statement of responsibility for providing identified services and programs. There are goals, mission statements, and aspirational objectives in the division documents which are not part of, nor reflected in, the comprehensive plan. Individual division directors were asked to include specific Olmstead planning in their overall annual management plans in order to avoid fragmentation of services or separation of the Olmstead specific population. These division plans and specific action steps are broader, and address all populations served by the respective divisions.

The following are division specific plans for serving the Olmstead population:

Division of Aging and Adult Services

- Identify barriers that prevent qualified seniors from moving back into the community from institutional settings, as well as potential partners and action steps to overcome these barriers.
- Identify barriers that prevent qualified seniors from remaining in their homes, as well as potential partners and action steps to assist in removing these barriers which provides
- Develop and implement the family caregiver support program statewide.
- Develop an online statewide resource directory.
- To insure that programs offered by the Division of Aging and Adult Services and the AAA's to enable seniors to be cared for in a community setting are having the desired effect, the Division and the Area Agencies have identified a series of outcomes for seven distinct services that will be measured on a regular basis. Over a period of 12 months a random sample of recipients of these services will be surveyed to document their perception of how well their needs are being met. Information will be used to continuously monitor the acceptance effectiveness of the programs. This effort will be accomplished through current appropriated budgets.

Division of Child & Family Services (DCFS)

Utah's Division of Child and Family Services (DCFS) is committed to meeting the needs of children who are placed in out-of-home care (family foster care, treatment foster care, shelter care, or residential care). The vast majority of these children have special needs. DCFS, through existing policy and practice strives to offer the least restrictive placement alternative to each child in our custody.

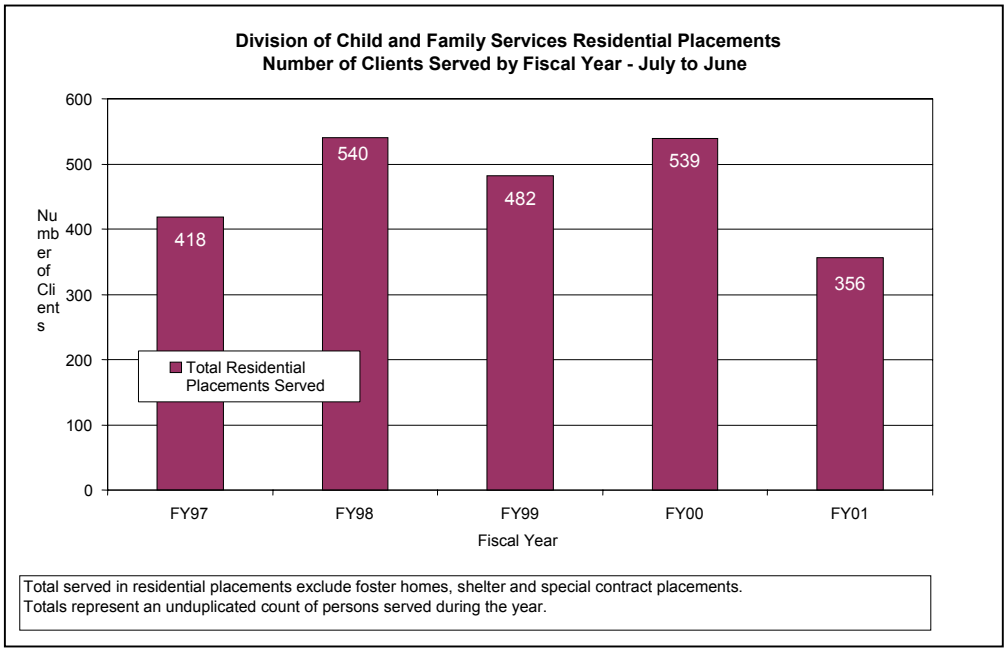
To assure that all children (including those with disabilities) are consistently placed in the least restrictive, most appropriate placement, a wide range of placement options must be maintained in all areas of the state. DCFS believes that beyond the need to provide care "in the most integrated setting appropriate to the child's needs", a least restrictive placement, in most cases, is one that allows the child to remain close to their family and community when out-of-home placement is required. The Division is committed to the following outcomes:

1. Through increased skill training, Child Protective Workers, with the assistance of Kin Locators in each Region, will successfully engage the family at the time of removal to jointly find an appropriate resource for children requiring out of home care.

2. By strengthening their approach to recruitment and training, DCFS will make more foster families who practice the Behavior Replacement Model of Care available statewide.

3. Caseworkers will be appropriately trained to know where and how to research appropriate resources, both formal and informal, for children in the custody of DCFS.

4. DCFS will develop "wraparound plans", similar to the Frontiers Project in the Southwest Region of DCFS, "wraparound" plans to provide individualized community-based services and natural supports individualized for the child and family.



Division of Mental Health (DMH)

- Adopt standardized preferred practice guidelines in the assessment of adults. These standardized guidelines would ensure statewide consistency in the delivery of mental health services. The goal is to provide a comprehensive assessment to identify the least restrictive appropriate level of treatment, for each consumer.
- Engage the Mental Health Planning Advisory group in continued *Olmstead* planning in order to outline the problem, need, potential partners and desired outcome on mental health issues.
- Hire a consultant to work with the *Olmstead* planning committee and the Division to develop the details of the plan and to coordinate it with the other *Olmstead* efforts within health and human services.
- A new Utilization Review Process Plan has been developed to coordinate the efforts of the Utah State Hospital (USH), the Division of Mental Health (DMH) and the Department of Health (DOH). This Plan brings together Health Care Financing

(HCFA) standards and hospital processes. The Plan is designed to monitor for compliance with all federal requirements and to implement safeguards to insure that the patient is receiving proper treatment and appropriate integration of USH services with community programs.

- DOH has retained two independent consultants to review USH programs, as well as the overall health system. They will provide recommendations for programs and alternate care options to provide services in the community whenever possible.
- DMH will continue conducting internal reviews of their monitoring process for the community mental health centers. DMH will continue to review best practices and to apply them to individual cases, and will include consumers and advocates in these reviews.
- Individual Case Review Process.
- Outline a process to assess a referral for community placement from any source. The process will include the following steps:
  - The client is referred for a case review from any source, such as USH, the local mental health centers, advocates, families, courts, the Disability Law Center, professionals, and others.
  - A review team is convened and provides a clinical assessment. The review team includes mental health professionals, a consumer advocate, a representative from an advocacy group, and a representative of DHS for cases that involve DHS clients.
  - *Olmstead* criteria is applied to the case:
    a) The State's treatment professionals determine whether community placement is appropriate.
    b) The affected person approves or opposes the community-based placement.
    c) The State determines whether it can reasonably accommodate the placement, taking into account the resources available to the State and the needs of others that are receiving State-supported disability services.
  - A system response explaining how DMH can best utilize existing resources to meet each client's needs.

Division of Services for People with Disabilities (DSPD)

- The division and department are engaged in efforts to address the waiting list in concert with the Legislative Auditors Office. It is anticipated these issues will be addressed by the Legislative in the 2002 session.
- DSPD will provide individuals with disabilities who are receiving division services:
  - the option of self-directed supports;
  - the option of using a micro-board;
  - local access to an independent, statewide self-advocacy network;
  - direct voting representation on boards, advisory groups and committees that make or influence decisions that directly impact their lives; and
  - choice of providers and service locations, along with the ability to initiate a request for a change of providers or locations at any time.

DSPD will also:

- extend service brokering to everyone on the waiting list;
- redirect administrative funds to program budgets;

- develop and implement a plan to address the immediate needs of those who are found eligible for services at their entry point and thereby prevent them from the wait for services that typically increases the need for more intrusive and costly services;
- develop new approaches to the waiting list, after considering shared ideas; and
- build capacity to assure availability of community-based services.

Division of Youth Corrections (DYC)

- length of stay in secure facilities as it relates to disabled individuals served.
- DYC will identify problems, perceived needs, potential partners and desired actions to address the following issues and populations:
  - secure facilities
  - sex offenders/ residential treatment
  - restrictive treatment centers
  - remote/isolated restrictive residential treatment

Division of Health Care Financing (DHCF)-Long-Term Care Unit

The Long Term Care Unit establish workload priorities to achieve the following objectives:

- Support and assist in the timely completion of the Action Plan identified in this "Comprehensive Plan for Public Services in the Most Appropriate Integrated Setting" as an element of the Medicaid long-term care program.
- Make "good faith" efforts to implement the strategies outlined in the "HealthPrint for Long Term Care" and the "Final Report of the Long Term Care Technical Advisory Group" as elements of the Medicaid long-term care program. (These two reports are available through the Department of Health.)
- Support the Level IV priorities of the Utah Department of Health and the Division of Health Care Financing.
- Monitor major long-term care initiatives and identify issues emerging on a national scale. Then evaluate their implications and the opportunities these initiatives and issues present for Utah's long-term care system.

Department of Workforce Services (DWS)

- DWS will identify the employment needs of persons with chronic illness and disabilities, and will develop strategies to address these needs.
- DWS will address workforce development issues related to the long-term care system.
- DWS will provide eligibility services for persons in community based settings.

APPENDIX

GLOSSARY and ACRONYMS

AAA's	Area Agencies on Aging
ADA	Americans with Disabilities Act
C-PAP	Continuous Positive Airway Pressure
CMS	Center for Medicaid and Medicare Services
DAAS	Division of Aging and Adult Services in the Department of Human Services
DCED	Department of Community and Economic Development
DCFS	Division of Child and Family Services in the Department of Human Services
DHCF	Division of Health Care Financing in the Department of Health
DHS	Department of Human Services
DLC	Disability Law Center
DMH	Division of Mental Health in the Department of Human Services
DOH	Department of Health
DRAC	Disabled Rights Action Committee
DSPD	Division of Services for People with Disabilities in the Department of Human Services
DWS	Department of Workforce Services
DYC	Division of Youth Corrections in the Department to Human Services
FY	Fiscal Year
HCBS	Home and Community-Based Services
HCFA	Federal Health Care Finance Administration
HIP	Hospital Improvement Program
HMO	Health Maintenance Organization
ICFs/MR	Intermediate Care Facility for Persons with Mental Retardation
LTC	Long Term Care
NAMI	National Alliance for the Mentally Ill
NF	Nursing Facilities
PERS	Personal Emergency Response Systems
TAG	Technical Advisory Group
TAP	The Alternatives Program
TBI	Traumatic Brain Injury
UBHN	Utah Behavioral Health Network
USDC	Utah State Developmental Center
USH	Utah State Hospital

ATTACHMENTS

Attachment 1: Principles to Guide the Delivery of Publicly Funded Services for People with Disabilities in Utah

Attachment 1

PRINCIPLES TO GUIDE THE DELIVERY OF PUBLICLY-FUNDED SERVICES FOR PEOPLE WITH DISABILITIES IN UTAH

March 8, 1999

1. Public agencies, providers of services, and consumers of services are always interdependent in their relationships. However, the preferences, values, and needs of the person with a disability shall guide the services and supports offered by the state.

2. In order to maximize a person's choice of services:

   A. The state will preserve and develop service options within allocated resources that people choose and that meet their needs.

      The current services and supports offered through the state, in partnership with a range of private providers, include: privately operated Intermediate Care Facilities for the Mentally Retarded; a publicly operated State Developmental Center; and publicly and privately operated home and community-based services ranging from family support/respite through day services, community living, and support coordination.

   B. The person will assume relevant responsibility and accept reasonable risk associated with the choices that he or she makes.

   C. In order to preserve the viability of service options, the state will employ an open enrollment period or some other orderly process to accommodate the individual selection of residential support.

   D. Choices that make claims on others may need to be negotiated to the satisfaction of the parties involved.

3. People, consistent with their disabilities, will be expected to work, participate in, and contribute to the communities in which they live. The state will support them in these efforts.

4. In order to maximize limited public resources to serve the largest number of individuals possible, based upon their needs, people will be provided the most economical supports of their choosing.

5. Designated funds shall first serve those with the most severe and critical needs.

6. Individuals and families should be encouraged to accept as much responsibility for care as is reasonable.

7. State agencies and providers of services must be accountable for providing quality services.

Developed by: Olene Walker (Utah Lieutenant Governor), Representative David Hogue, Representative Judy Ann Buffmire, Mary Paulsen (parent advocate), Cathy Chambless (Executive Director of the Governor's Council for People with Disabilities), Sue Behle (Executive Director of the Utah Association of Community Services), Joan Gallegos (Director of Utah HealthCare Association), Rod Betit (Executive Director of the Utah Department of Health), Robin Arnold-Williams (Executive Director of the Utah Department of Human Services), Sue Geary, (Director of the Division of Services for People with Disabilities), Michael Deily (Director of the Division of Health Care Financing), Kim Hood (Policy Analyst in the Governor's Office of Planning and Budget), and Stephen Jardine (Policy Analyst in the Governor's Office of Planning and Budget).